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ORIGINAL ARTICLE

Involvement of supportive care professionals in patient care in the last month of life

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Abstract
Background In the last month of life, many patients suffer from multiple symptoms and problems. Professional supportive care involvement may help to alleviate patients' suffering and provide them with an optimal last phase of life.
Purpose We investigated how often palliative care consultants, pain specialists, psychological experts and spiritual caregivers are involved in caring for patients in the last month of life, and which factors are associated with their involvement.
Methods Questionnaires were mailed to physicians who had attended the death of a patient from a stratified sample of 8496 deaths that had occurred in 2010 in the Netherlands. The response rate was 74 % (n=6263).
Results A palliative care team or consultant had been involved in the last month of life in 12 % of all patients for whom death was expected; this percentage was 3 % for pain specialists, 6 % for psychologists or psychiatrists and 13 % for spiritual caregivers. Involvement of palliative care or pain specialists was most common in younger patients, in patients with cancer and in patients who died at home. Involvement of psychological or spiritual caregivers was most common in older patients, in females, in patients with dementia and in patients who died in a nursing home. Involvement of supportive caregivers was also associated with the use of morphine and end-of-life decisions.
Conclusion Supportive care professionals are involved in end-of-life care in about a quarter of all non-suddenly dying patients. Their involvement is related to the setting where patients die, to the patient's characteristics and to complex ethical decision-making.

Keywords Supportive care · Palliative care · Consultation · End-of-life decision-making

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Introduction

At the end of life, patients with cancer or other life-threatening diseases may develop a variety of symptoms and problems, either physical, psychological or spiritual, which can be distressing and detrimental to their quality of life [1–5]. In patients with incurable cancer, symptoms like fatigue, pain, lack of energy, weakness and appetite loss occur in more than 50 % of the patients [2]. Patients with advanced chronic obstructive pulmonary disease and chronic heart failure reported multiple symptoms that are often undertreated [6], and inappropriate symptom treatment has been reported for patients with dementia [7, 8].

Palliative and supportive care aim to relieve suffering and improve the quality of life for patients with advanced illnesses and their families. It is based on an interdisciplinary approach that can be offered simultaneously with disease-oriented treatment and involves attention to the emotional, spiritual and practical needs and goals of patients and of the people who are close to them [9, 10]. Although there is discussion about the terminology, there is considerable overlap between palliative and supportive care [11]. The phrase 'palliative care' is in principle used for patients with a limited life expectancy due to an incurable disease, whereas the phrase 'supportive care' can be used for all patients with chronic diseases. Both focus

on symptom management, psychosocial care, communication, complex decision-making and transition of goals of care [12]. There is growing evidence that palliative care improves the quality of the last phase of life for patients [13–17] and their relatives [18, 19].

In a study by Murtagh et al., based on underlying and contributory causes of death, it was estimated that in high-income countries, between 69 and 82 % of those who die need palliative care [20].

In the Netherlands, palliative and supportive care are mainly provided by general health care professionals [21]. There is a strong emphasis on primary care which is professional health care as provided in the community, usually by a general practitioner (GP), home care nurses and sometimes other health professionals; almost one third of all deaths in the Netherlands occur in the home setting [22]. Palliative care is not officially recognized as a medical specialty, but there are professionals who are trained in palliative care. It is acknowledged that in some cases, palliative care experts are needed to provide symptom relief, psychosocial support or support in end-of-life decision-making. This awareness has resulted in a growing attention for palliative care and an increasing number of palliative care services such as hospices, palliative care units in nursing homes and palliative care consultation services, over the past years [23]. Since 1996, the Dutch Government developed a policy to support and enhance palliative care. At the moment, there are 25 palliative care consultation teams, covering all of the country [24]. These teams can be consulted by all professionals involved in palliative care, but in practice, they are mainly consulted by general practitioners [24]. The aim of these teams is not to take over care, but to inform, support and advise the attending professional caregivers [21]. More recently, both hospitals and nursing homes are developing palliative care consultation services [25].

According to the WHO definition, all patients with a life-threatening illness could benefit from palliative care [10]. Until now, it is not known how often general caregivers involve professionals specialized in supportive or palliative care for patients who are in the last phase of life and which factors are associated with the involvement of these caregivers. We performed an observational study to answer the following research questions:

1. How often are palliative care consultants, pain specialists, psychologists, psychiatrists and spiritual caregivers involved in caring for patients in the last month of life?
2. Which characteristics of patients and the setting where they are being cared for are associated with the involvement of supportive care professionals?
3. Which end-of-life decisions are associated with the involvement of supportive care professionals?

Materials and methods

Study design and data collection

In 2010, a cross-sectional study was performed. A stratified sample was drawn from the central death registry of Statistics Netherlands, which receives death certificates for all deaths in the Netherlands. When the cause of death was one in which it was clear that no physician's assistance in dying could have been provided (e.g. instant death in a traffic accident), cases were assigned to stratum one. On the basis of cause of death, cases were assigned to one of the other strata looking at the likelihood that an end-of-life decision had preceded death: when this decision was unlikely (e.g. acute myocardial infarction or aneurysm), cause of death was allocated to stratum two, when this decision was possible (e.g. heart failure or Parkinson's disease) to stratum three and when this decision was more probable (e.g. cancer) to stratum four. Cases were assigned to stratum five when the physician had noted on the death certificate that they had actively ended the life of the patient. The final sampling contained 50 % of the cases in stratum five, 25 % of the cases in stratum four, 13 % of those in stratum three and 8 % of those in strata one and two. All attending physicians of the sampled cases in strata two to five received a questionnaire [26].

Population and setting

The sample was drawn from all deaths that had occurred between August 1 and November 30 in 2010 (n=8496). A written questionnaire was mailed to the attending physician. Of the 8496 mailed questionnaires, 6263 were returned resulting in a response rate of 74 %. Responding physicians represented all health care settings: general practitioners providing care for patients living at home and in care homes, elderly care physicians providing care in nursing homes and medical specialists providing care in hospitals.

Questionnaire

The attending physician was requested to complete the four-page questionnaire, containing mainly multiple choice questions. The questionnaire focused on the characteristics of the end-of-life decision-making that may have preceded the death of the patient involved. The wording of these questions was validated in previous studies that were performed in 1990 and 1995, and was kept identical in subsequent studies that were performed in 2001, 2005 and 2010. In 2010, questions on medical treatment and care in the last phase of life were added. These included the question 'Which caregivers were involved in caring for the patient in the last month of life?' Respondents could choose from five options: a palliative care consultant or palliative care team, a pain specialist, a psychologist or psychiatrist, a spiritual caregiver (or chaplain) or +another professional.

Statistical analysis

We analysed data for patients whose death was reported to have occurred non-suddenly. Multivariable logistic regression analysis was performed with SPSS version 20 to identify factors associated with the involvement of different care professionals. In case of the question regarding the involvement of supportive care professionals, respondents sometimes mentioned 'other professionals' who could be recoded to one of the four professions of interest. In multivariable logistic regression models to assess factors associated with involvement of supportive caregivers, we combined the involvement of palliative care consultants, palliative care teams and pain specialists, because we assumed that these specialties mainly focus on physical causes of suffering. We also combined involvement of psychologists, psychiatrists and spiritual caregivers, assuming that these specialties mainly focus on non-physical causes of suffering. For both types of supportive caregivers, we assessed whether their involvement was associated with patient characteristics (age, gender, diagnosis), place of death, hospitalization during the last month of life and the aim of care during the last phase of life (palliation or life prolongation). A second multivariable logistic regression analysis was performed to assess associations between the involvement of supportive caregivers and the use of morphine in the last 24 h before death, the use of continuous deep sedation and different types of end-of-life decisions (forgoing life-prolonging treatment, intensive forms of alleviation of symptoms and euthanasia).

Results

Involvement of supportive care professionals in the last month of life

Table 1 shows that in 27 % of all cases of patients who had died a non-sudden death, one or more supportive caregivers had been involved in the care in the last month of life. Three percent of all non-sudden deaths had involved care of a pain specialist, in 12 % a palliative care team or palliative care consultant had been involved, in 6 % a psychiatrist or psychologist and in 13 % a spiritual caregiver.

Table 1 Involvement of supportive care professionals in the last month of life

	Non-sudden deaths in the Netherlands in 2010 (n=4930) % (n)
Palliative care team/consultant	12 (785)
Pain specialist	3 (246)
Psychologist/psychiatrist	6 (263)
Spiritual caregiver	13 (613)
Any supportive caregiver	27 (1540)

All percentages are weighted for sampling fractions, non-response and random sampling deviations, to make them representative for all non-sudden deaths in the Netherlands in 2010

In the multivariable logistic regression model, involvement of palliative care or pain specialists was most likely for patients aged 0–64 (26 %, odds ratio (OR)=2.28, confidence interval (CI) 1.79–2.89) or 65–79 years (20 %, OR=1.91, CI 1.55–2.36), for patients who were diagnosed with cancer (28 %, OR=2.58, CI 2.03–3.28), for patients who were hospitalized in the last month of life (17 %, OR=1.28, CI 1.06–1.53) and for patients who died at home (20 %, OR=1.29, CI 1.01–1.66) or in a nursing home (10 %, OR=1.40, CI 1.04–1.89). Palliative care and pain specialists were rarely consulted for patients diagnosed with dementia (4 %, OR=0.39, CI 0.27–0.55). Palliative care and pain specialists were also more often consulted for patients for whom care had been aimed at palliation during the last weeks or months of life (21 %, OR=3.98, CI 2.93–5.41) or days of life (14 %, OR=3.11, CI 2.26–4.27) (Table 2).

Involvement of psychological or spiritual caregivers was most common for patients aged 64–79 years (17 %, OR=1.32, CI 1.09–1.59), for female patients (19 %, OR=1.31, CI 1.11–1.54) and for patients who died in a nursing home (33 %, OR=3.67, CI 2.83–4.75). Psychological or spiritual caregivers were also more often consulted for patients for whom care had been aimed at palliation during the last weeks and months of life (23 %, OR=2.19, CI 1.73–4.75) (Table 3).

Associations between involvement of supportive caregivers and end-of-life care and end-of-life decision-making

In a multivariable logistic regression model, involvement of pain or palliative care specialists was associated with an increased likelihood that the patient had received morphine in the last 24 h before death (OR=2.03, CI 1.59–2.59), continuous deep sedation (OR=2.26, CI 1.80–2.74), euthanasia or physician-assisted suicide (OR=1.47, CI 1.06–2.03) and intensive alleviation of symptoms with a potential risk of hastening death (OR=1.39, CI 1.17–1.64) (Table 4). Involvement of psychological or spiritual caregivers was associated with a higher likelihood that the patient had received morphine in the last 24 h before death (OR=1.72, CI 1.40–2.11) and intensive alleviation of symptoms (OR=1.51, CI 1.29–1.76) and that potentially life-prolonging treatment had been withdrawn or withheld (OR=1.26, CI 1.08–1.48).

Discussion

Involvement of supportive caregivers in the last month of life

This study shows that in the Netherlands, supportive care specialists are involved in patients' care in the last month of life in

Table 2 Patient and care characteristics associated with involvement of palliative care and pain specialists in the last month of life

Palliative care and pain specialist involvement					
		% (column)	% (row)	Univariate logistic regression OR (95 % CI)	Multivariate logistic regression OR (95 % CI)
Overall	5062		14.0		
Age					
0–64	1312	16.0	26.3	*4.50 (3.66–5.54)*	*2.28 (1.79–2.89)*
64–79	1663	30.2	19.5	*3.06 (2.55–3.68)*	*1.91 (1.55–2.36)*
>80 (ref)	2087	53.8	7.3	1	1
Sex					
Female	2518	53.5	12.4	*0.76 (0.65–0.89)*	0.96 (0.81–1.15)
Male (ref)	2544	46.5	15.7	1	1
Cause of death					
Cardiovascular disease	543	16.5	6.0	1.07 (0.78–1.48)	1.05 (0.75–1.49)
Cancer	2925	37.2	27.9	*6.54 (5.37–7.95)*	*2.58 (2.03–3.28)*
Other or unknown (ref)	1594	46.3	5.6	1	1
Dementia					
Yes	739	23.0	4.0	*0.20 (0.15–0.27)*	*0.39 (0.27–0.55)*
No (ref)	4104	77.0	17.2	1	1
Place of death					
Home and residential home	2663	42.8	20.0	*2.53 (2.07–3.10)*	*1.29 (1.01–1.66)*
Nursing home	1122	28.5	9.8	1.11 (0.87–1.41)	*1.40 (1.04–1.89)*
Hospital (ref)	1277	28.7	9.0	1	1
Hospitalization in the last month of life?					
Yes	1815	35.5	17.0	*1.43 (1.22–1.67)*	*1.28 (1.06–1.53)*
No (ref)	3027	64.5	12.5	1	1
Was care prior to death aimed at palliation?					
Yes, during the last weeks/months of life	2626	47.9	20.7	*5.74 (4.42–7.46)*	*3.98 (2.93–5.41)*
Yes, during the last days of life	892	21.4	14.2	*3.65 (2.72–4.91)*	*3.11 (2.26–4.27)*
No, or only in the last hours of life	1136	30.7	4.3	1	1

All percentages are weighted for sampling fractions, non-response and random sampling deviations, to make them representative for all deaths in the year studied

ref reference category, *OR (95 % CI)* odds ratios and 95 % confidence intervals

a minority of cases: a palliative care team or consultant was involved in 12 % of all non-sudden deaths, a pain specialist in 3 %, a psychologist or psychiatrist in 6 % and a spiritual caregiver in 13 %. The involvement of palliative care teams or consultants is low compared to that in other countries, e.g. Australia, where specialist palliative care services are involved in approximately 37.5 % of the total number of people who are expected to die each year [27].

We found substantial differences in the use of supportive caregivers in different patient groups. Psychological and spiritual caregivers were more often consulted in patients who die in the nursing home. This is probably due to the availability of these caregivers in nursing homes where, besides elderly care physicians, psychologists, pastoral workers and other disciplines are part of the multidisciplinary team [28]. Palliative care and pain specialists were more often consulted for younger patients and patients who died of cancer, whereas patients with dementia had a lower likelihood of involvement of these caregivers. It can be questioned whether this is due to different palliative care needs, e.g. because of differences in disease trajectories or in the complexity of the patient's situation, or whether this reflects potential barriers in access to palliative care services. Substantial symptom burden has been reported for patients with varying diagnoses, such as cancer, dementia and COPD or heart failure [6–8]. It is known that there are many barriers to the adequate use of palliative care, such as late referral, lack of physician knowledge on palliative care and communication skills, the view that involving palliative care specialists is a signal that all hope for a patient is given up, health care providers' interpretation of the death of a patient as a failure and the lack of awareness of the availability of

Table 3 Patient and care characteristics associated with involvement of psychological and spiritual caregivers in the last month of life

Psychological and spiritual caregiver involvement					
		% (column)	% (row)	Univariate logistic regression OR (95 % CI)	Multivariate logistic regression OR (95 % CI)
Overall	5062		16.3		
Age					
0–64	1312	16.0	13.0	*0.73 (0.58–0.91)*	1.16 (0.89–1.51)
64–79	1663	30.2	16.7	0.98 (0.83–1.15)	*1.32 (1.09–1.59)*
>80 (ref)	2087	53.8	17.0	1	1
Sex					
Female	2518	53.5	19.0	*1.53 (1.32–1.78)*	*1.31 (1.11–1.54)*
Male (ref)	2544	46.5	13.2	1	1
Cause of death					
Cardiovascular disease	543	16.5	12.5	*0.63 (0.50–0.79)*	1.01 (0.79–1.29)
Cancer	2925	37.2	15.4	*0.80 (0.69–0.94)*	1.16 (0.93–1.44)
Other or unknown (ref)	1594	46.3	18.4	1	1
Dementia					
Yes	4104	23.0	26.9	*2.35 (2.02–2.75)*	1.08 (0.87–1.34)
No (ref)	739	77.0	13.5	1	1
Place of death					
Home and residential home	2663	42.8	10.1	1.17 (0.93–1.45)	0.78 (0.60–1.01)
Nursing home	1122	28.5	33.0	*5.10 (4.15–6.26)*	*3.67 (2.83–4.75)*
Hospital (ref)	1277	28.7	8.8	1	1
Hospitalization in the last month of life?					
Yes	1815	35.5	13.6	*0.71 (0.61–0.83)*	1.09 (0.91–1.32)
No (ref)	3027	64.5	18.1	1	1
Was care prior to death aimed at palliation?					
Yes, during the last weeks/months of life	2626	47.9	22.8	*2.82 (1.22–1.97)*	*2.19 (1.73–2.76)*
Yes, during the last days of life	892	21.4	13.9	*1.55 (1.22–1.97)*	1.26 (0.98–1.63)
No, or only in the last hours of life	1136	30.7	9.5	1	1

All percentages are weighted for sampling fractions, non-response and random sampling deviations, to make them representative for all deaths in the year studied

ref reference category, *OR (95 % CI)* odds ratios and 95 % confidence intervals

palliative care services [29–34]. This may probably explain the fact that not all patients have equal access to palliative care. For elderly patients, ethnic minority groups, patients with lower socioeconomic status and other disadvantaged groups, poor access to palliative care has been reported before [35]. Some subpopulations are less often referred to palliative care services such as patients with non-cancer diagnoses [36, 37].

On the other hand, not everyone facing a life-limiting illness needs specialist palliative caregivers [36]. In the Netherlands, all health care professionals are supposed to be capable of providing general palliative care, which can, when necessary, be complemented by specialist palliative care that should be readily available [38]. This is in line with a model described by Quill and Abernethy that distinguishes primary palliative care (skills all clinicians should have) from specialist palliative care (skills for managing more complex and difficult cases), coexisting and supporting each other [39]. However, in the Netherlands, it is not yet clear how basic or general palliative care and specialist palliative care are defined and can be distinguished. In this study, the need for specialist palliative care was not investigated, and therefore, we cannot draw firm conclusions regarding under- or overuse of supportive care.

Supportive care and end-of-life care and decision-making

In order to prevent or alleviate suffering at the end of life, end-of-life decisions can be made, such as forgoing burdensome treatment and intensifying alleviation of pain or other symptoms. In this study, we found that involvement of supportive caregivers was associated with a higher likelihood of use of

Table 4 Association between involvement of supportive care professionals and use of morphine, continuous deep sedation and end-of-life decisions

Involvement of supportive caregivers		*N*, 4930	Morphine in the last 24 h before death		Continuous deep sedation		Euthanasia or physician-assisted suicide		Intensive alleviation of symptoms		Forgoing life-prolonging treatment	
			%	OR (CI)	%	OR (CI)	%	OR (CI)	%	OR (CI)	%	OR (CI)
Palliative care/pain specialist	Yes	958	88.1	2.03 (1.59–2.59)	28.5	2.26 (1.80–2.74)	8.7	1.47 (1.06–2.03)	63.7	1.39 (1.17–1.64)	36.1	0.95 (0.80–1.13)
	No (ref)	3972	73.6	1	13.6	1	2.9	1	55.4	1	48.5	1
Psychological/spiritual caregiver	Yes	788	84.2	1.72 (1.40–2.11)	15.4	1.18 (0.95–1.45)	3.9	1.11 (0.72–1.73)	65.2	1.51 (1.29–1.76)	52.0	1.26 (1.08–1.48)
	No (ref)	4142	73.9	1	15.7	1	2.9	1	54.9	1	45.7	1

All percentages are weighted for sampling fractions, non-response and random sampling deviations, to make them representative for all non-sudden deaths in 2010

OR (CI) odds ratios and 95 % confidence intervals, *ref* reference category

morphine in the last 24 h before death and with patients receiving intensive forms of alleviation of symptoms, such as continuous deep sedation. This is not surprising as supportive caregivers will be consulted more often in complex situations. The latter may be related to the requirement in the national guideline for use of palliative sedation of the presence of refractory symptoms [40]. When suffering becomes unbearable, patients may ask for the hastening of death, which is allowed under strict regulation in the Netherlands [26]. Involvement of pain and palliative specialists was also associated with a higher likelihood of receiving euthanasia. This is in line with an earlier study in which involvement of palliative care teams and psychiatrists was positively associated with patients requesting euthanasia [41]. As our study had a cross-sectional design, we cannot conclude that there is a causal relationship between involvement of supportive care professionals and end-of-life decisions, but our data suggest that the involvement of supportive caregivers does not prevent euthanasia or other end-of life decisions.

Strengths and limitations

A strength of this study is the large number of deaths that was studied (n=6263). Furthermore, cases were obtained from a nationwide, representative sample, and the response rate was high (74 %).

A limitation is that the questionnaire was filled in by the physician who attended patients' death. This may not always have been the physician who was the attending caregiver in the period that preceded death, which may imply that the physician might not have been aware of all caregivers that were involved. This may have resulted in an underreporting of the involvement of the different caregivers, especially of spiritual caregivers, because physicians may not always be aware of the involvement of spiritual caregivers. In our questionnaire, we combined 'psychologists' and 'psychiatrists'. It may not have been proper to combine psychologists and spiritual caregivers (non-physicians), with psychiatrists (physicians). Furthermore, we did not assess the effects of the involvement of these supportive caregivers, e.g. on patients' quality of life.

Recommendations

This study provides insight in patterns in the use of supportive and palliative care in the last month of life. Further insight in whether people with life-limiting illnesses who do not access specialized palliative or supportive care services have unmet needs is crucial in planning and evaluating palliative care. It would be desirable to structurally monitor the use of palliative and supportive care on a regular basis.

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